

## **Audience Notes from the Kansas City Alzheimer's State Task Force Town Hall Meeting**

April 8, 2010

### **Audience Comments/Responses:**

- Caregiver from Kansas City, Missouri (wife had the disease) shared frustration with Medicaid system which did not afford his wife sufficient assistance in the home and forced him to place earlier than he wanted to.
- Caregiver from Lee's Summit, Missouri (mom has the disease) cited concerns with the following issues
  - 1) Cost of Prescription Drugs
  - 2) Lack of Memory Care Assisted Living in the State
  - 3) Physician Competence in early detection
  - 4) Insufficient training in how to care for individuals with Alzheimer's disease among health care professionals, especially the acute hospital setting
- Caregiver from Raymore, Missouri (mom has the disease) conveyed concerns about:
  - 1) Long Term Care Staff insufficiently trained
  - 2) Poor staff ratios in facilities which do not allow for quality care to be provided.
- Caregiver from Kansas City, Missouri (mom has the disease) indicated needs in the following areas:
  - 1) Would have liked to keep her mom at home but wasn't possible because of the funding and differing Medicaid support for in home versus facility.
  - 2) She could not afford to quit work to care for her mom, and mom couldn't afford to pay her, but if she could have been paid the amount that Medicaid paid the nursing home, she would have been able to keep her mom at home
- Caregiver, Platte City, Missouri (cares for her dad) shared frustration regarding the experience of her dad being financially exploited. She talked with police, APS and the Attorney General and was told there was nothing they could do. She feels there is a significant need for a specific division or department (forensic auditors?) to investigate and prosecute financial exploiters.
- Caregiver, Kansas City, Missouri (cared for grandparents with the disease) discussed the need for client based care in the facilities, including availability of private rooms for people with the disease even if they are on Medicaid.
- Caregiver, Kansas City, Missouri (husband had younger onset, died at the age of 52) conveyed need for unique criteria for physical therapy engagement for those

with Alzheimer's disease. She had the experience of P.T. having to be terminated because he was not improving, but the P.T. reduced deterioration and she felt if it could have been continued, she would have been able to keep him at home longer and he would have had improved quality of life.

- Caregiver, Kansas City, Missouri (mom has the disease) expressed the following:
  - 1) Need for more legal information at point of diagnosis
  - 2) Need "checklist" of things to consider before diagnosis progresses and the person is no longer able to participate in decisions/planning
  - 3) Legal assistance is too expensive to utilize as fully as needed.
  - 4) Physicians do not refer to support services like the Alzheimer's Association, give diagnosis without sufficient conversation about that and sends people on their way.
- Caregiver, Lee's Summit (mom has the disease, is in placement in Clinton, Missouri) affirms what others conveyed about need for increased financial help to keep their loved one at home.
- Professional, District 7 AAA (MARC). Conveyed that there are more Memory Care Assisted Living options on the Kansas side, limited options in this area on the Missouri side
- Caregiver, Platte County (father died with Alzheimer's in 2008) echoed frustration with physicians who did not refer to the Alzheimer's Association or other support services nor give sufficient information for families to react/plan for existing and anticipated needs. Also discussed the heaviness of the financial burden.
- Professional, Kansas City, Missouri. (Director of Senior Companions) Discussed the Senior Companion Program here (a service that provided limited free companion services) and the value she sees it offers.
- Professional and Caregiver, Bethany, Missouri. She conveyed need for more support groups in every town and the need for individualized support 24 hours a day, 7 days a week to assist families with the crisis and struggles that occur in this disease.
- Gwen Richards, Kansas City, Missouri (person with Alzheimer's as well as Task Force member) discussed her personal journey and awareness of the shortage of Missouri options compared to Kansas.
- Professional, Lee's Summit, Missouri (Police Officer who coordinates Project Lifesaver in that jurisdiction) affirmed CIT efforts in the area, but continues to feel more training needed for law enforcement.

- Professional, Kansas City, Missouri (Professional Geriatric Case Manager) echoed need for increased memory care assisted living on the Missouri side.
- Caregiver, Kansas City Missouri (mom has the disease) affirmed need for more memory care assisted living options on the Missouri side and the need to change Medicaid qualifications for those individuals who live at home.
- Caregiver, Kansas City, Missouri – Clay county (dad has the disease) expressed concerns regarding too few adult day programs and too little financial assistance to help with the few that exist.
- Professional, Kansas City Missouri – expressed need for increased hours for dementia training for individuals working in adult day programs.
- Caregiver, Kansas City, Missouri – (mom has AD) discussed need for more case management services.
- Caregiver, Kansas City, Missouri, expressed concerns that there was little for her mom when she was in early stage of the disease. Feels that more services need to be directed to early stage and early onset.